

Euthanasia in the Netherlands

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The practice of euthanasia in the Netherlands is often used as an argument in debates outside the Netherlands—hence a clear description of the Dutch situation is important. This article summarises recent data and discusses conceptual issues and relevant characteristics of the system of health care. Special emphasis is put on regulation, including relevant data on notification and prosecution. Besides the practice of euthanasia the Dutch are confronted with the gaps in reporting of cases to the public prosecutor and the existence of cases of ending a life without an explicit request. Nevertheless, the “Dutch experiment” need not inevitably lead down the slippery slope because of the visibility and openness of this part of medical practice. This will lead to increased awareness, more safeguards, and improvement of medical decisions concerning the end of life.

Introduction

The practice and regulation of euthanasia and assisted suicide in the Netherlands has attracted much attention. Opponents feel that the practice of euthanasia in the Netherlands must be presented as a deterrent to euthanasia elsewhere,¹⁻⁶ but others view the situation in the Netherlands as an important development suggesting changes within their own countries or states.⁷⁻¹² Since trustworthy empirical data have not been available until recently, moral viewpoints have coloured the estimated numbers of cases of euthanasia (and assisted suicide) and the way in which it is practised. Recent reports, however, have diminished this empirical uncertainty.¹³⁻¹⁸

One of the main concerns with regard to euthanasia is whether sufficient safeguards are possible. In turn, in pluralistic societies this form of the “slippery slope” argument is the most important argument against legalisation of euthanasia.^{19,20} This article describes the situation in the Netherlands, with special emphasis on regulation, including relevant data on notification and prosecution.

Conceptual issues

Particular conceptual demarcations with regard to euthanasia and other medical decisions concerning the end of life are important. These decisions can be categorised in several ways, based on the intention of the physician, the distinction between acting and refraining, the presence of informed consent, and the explicitness of the patient's request. In the Netherlands euthanasia is defined as someone other than the patient intentionally ending the life of a patient at the patient's request. Euthanasia and assisted suicide are different acts, with different responsibilities for the physician. Since both acts bring about death they can be seen as morally similar, although the fact that in assisted suicide the patient brings about his or her own death must be seen as an important difference.²¹

Three important points are implied by these definitions. Firstly, euthanasia and assisted suicide are acts; they are defined as doing something, usually handing over or administering a drug. They are not defined as refraining from action—that is, not starting or

stopping a treatment (not even by the action of changing the switch of the ventilator). Secondly, euthanasia and assisted suicide are defined as voluntary (at request), thereby excluding particular patients, such as newborn infants or comatose patients. Thirdly, the term “intentionally” is usually interpreted as “with the primary intention of.” Thus the treatment of pain, for example by high doses of morphine, with the secondary effect of shortening the life span, is not considered to be euthanasia.

Health care system and insurance

Health care in the Netherlands (15 million inhabitants, 129 000 deaths in 1990) has some features that allow the practice of euthanasia and other decisions concerning the end of life to be free from restraint and coercion. There is a strongly developed system of primary care with 6300 general practitioners and additional (nursing) care at home. Many patients (40%) die at home, especially patients with cancer (48% of all cancer deaths). There is a well developed system of care in nursing homes (covering 16% of all deaths and 5% of all cancer deaths) that is unique in the Netherlands, and there are more beds in nursing homes than in hospitals. Moreover, nursing home medicine is a distinct medical specialty, having its own licensing authorities. The hospital system and specialist medical care are also of a uniformly high quality. The nursing staff has a well developed professional attitude and background and is usually involved in the decision making process. Almost all patients (99.4%) have health care insurance, and 100% of the population is insured for the cost of protracted illness. There are no financial incentives for hospitals, physicians, or family members to stop the care of patients. Moreover, the legal right of patients to health care on the basis of their insurance will override budget and other financial agreements.

Empirical data on euthanasia

Van der Maas *et al* recently reported the results of interviews with 405 physicians, postal questionnaires to the attending physicians of a sample of 7000 deceased patients, and a prospective study among the interviewed physicians regarding 2250 deaths.¹³⁻¹⁵ Van der Wal *et al* examined 263 police reports and carried out extensive surveys among more than 1000 general practitioners and virtually all nursing home physicians in the Netherlands (675 doctors), using a written questionnaire.^{16-18,22} The results of both research groups were similar. Both studies were based on self reports of doctors obtained in strict anonymity, without the data being communicated to the legal authorities (except for the police reports).

Van der Maas *et al* found that there were 2300 cases of euthanasia and 400 cases of assisted suicide in the Netherlands in 1990 (1.8% and 0.3% of all deaths).^{13,14} The number of initial requests was around three times as high, indicating that in many cases alternatives were found, patients changed their minds, the doctor turned down the request, or the patient's life ended naturally. Van der Wal *et al* found that general practitioners were involved in around 1500 cases of euthanasia and 500

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cases of assisted suicide each year during the period 1986-9. In the same period there were around 5000 requests yearly.¹⁶ In nursing homes, by contrast, there were 275-300 requests for euthanasia and 25 cases of euthanasia.²² In general, euthanasia occurs at home in one out of about 25 deaths, in hospitals in one out of 75, and in nursing homes in one out of 800.

In almost all cases of euthanasia and assisted suicide the patients were terminally ill; in 58% of all cases the shortening of life was estimated to be one week at most and in 83% less than one month. Almost three quarters of the patients requesting euthanasia had cancer (the cancer death rate in the Netherlands is 27%).¹⁴ Most patients dying at home (85%) had malignant diseases. Over the age of 75 and especially over 80 euthanasia was only rarely applied.^{14,18} The most important reasons for the request for euthanasia were futile suffering (29%), avoidance of humiliation (24%), and unbearable suffering (18%). Although pain was among the reasons in 40% of cases, only in 5% of cases was pain mentioned as the most important reason.¹⁷ Van der Maas *et al* found similar results.¹⁴

Other medical decisions concerning the end of life

Van der Maas *et al* also addressed other medical decisions concerning the end of life. These authors estimated that in more than 1000 cases a year (0.8% of all deaths) doctors prescribed or administered a drug with the explicit goal of shortening the patient's life, without an explicit request by the patient. This decision is most often made in hospital (710 times yearly), less often in general practice (270) and nursing homes (50).²³

More than half of these cases (59%) had information about the patient's wish, but not an explicit request. In most cases the patients were in the end stage of a malignant disease and were dying; in 86% of the cases shortening of life was less than a week. In 56% of the cases the patient was considered to be incompetent.²³ The results of Van der Wal *et al* with regard to the ending of life by general practitioners without an explicit request from the patient largely confirmed those of Van der Maas *et al*.¹⁸ Ending of life is very rare in severely handicapped newborn infants (less than 10 cases a year) and patients in persistent vegetative state (one case reported so far).

In 17.5% of the 129 000 deaths in 1990, alleviation of pain and symptoms was such that a shortening of the patient's life could not be ruled out. In 80% of the cases this possible side effect was accepted, but not intended. In 20% shortening of life was obliquely intended (in 6% explicitly according to interviews^{13,14}). More than half of the patients had been consulted; in the remaining cases consultation was not possible in 88%. Almost a quarter of these patients had previously stated that they desired a hastening of death.^{13,14}

In another 17.5% of all the deaths treatment had not been started or had been stopped, with the acceptance that this could hasten the death of the patient. In almost half of the cases hastening of death was obliquely intended. The shortening (or rather, not lengthening) of life as a result of not starting (or stopping) a treatment was more than a month in 17% of cases when treatment was not started and in 4% when treatment was stopped. Of the patients 59% and 64%, respectively, were not consulted. In the remaining cases, consultation was not possible in 94%, whereas 16% of the patients had previously stated that they wished hastening of death.^{13,14}

Legal position of doctors

In the Netherlands the legal position is now clear but paradoxical. Euthanasia and assisted suicide are still

subject to criminal law. The maximum punishment for euthanasia is 12 years' imprisonment; for assisted suicide it is three years. Hence, a doctor is formally open to criminal prosecution.²⁴

This does not imply, however, that all doctors who have performed euthanasia or assisted suicide are actually prosecuted. During recent years court decisions have developed so as to indicate that euthanasia is not a regular medical act, but that doctors will not be judged guilty if they perform euthanasia and assisted suicide in a prudent way. The legal basis of this verdict is the force majeure wherein the doctor must act. The doctor is confronted with conflicting obligations: towards the patient as a caregiver, and towards the law as a civilian. Professional obligations force the doctor to act against the formal provisions of the law but in accordance with viewpoints developed in medical ethics and in accordance with the explicit wish of the patient who relies on him or her.

In addition, there are substantive requirements a doctor must meet when performing euthanasia or assisted suicide. These were published by the General Board of the Royal Dutch Medical Association in 1984 and have been confirmed in court decisions. The requirements are cumulative: voluntary and durable request; full information; intolerable and hopeless suffering; no acceptable alternatives left; and consultation with another physician. In general, a doctor will not be prosecuted if acting according to these requirements.

In 1990 the Royal Dutch Medical Association and the Ministry of Justice agreed on a notification procedure. The doctor does not issue a declaration of a natural death; the doctor informs the medical examiner by means of an extensive questionnaire; and the medical examiner reports to the public prosecutor, who decides whether a prosecution must be started.

Bill 22572

The study by Van der Maas *et al* was carried out at the request of a committee of inquiry, the Remmelink committee, which was set up by the government in 1990 to investigate medical decisions concerning the end of life. In November 1991, on the basis of the committee's report,¹⁵ the government set out its position on future legislation and announced a new legislative proposal, which was accepted by the Lower House on 9 February 1993 and by the Senate on 30 November 1993 (Bill 22572). The new act is an amendment to the Burial Act and is predominantly procedural in character. The penal code will not be changed. However, the notification procedure for cases of euthanasia and assisted suicide which was agreed in 1990 will be laid down in regulations under the Burial Act and thereby acquire formal legal status.

The requirements of careful medical practice concerning euthanasia are not explicitly mentioned in the act. As a canonical statement of these requirements has not been provided by the legislator, these requirements have to be derived from court decisions. The regulations under the Burial Act will contain an appendix with a questionnaire (to be answered by the doctor when reporting to the medical examiner) which is indirectly related to the requirements of careful medical practice.

Notification and prosecution

Before 1985 doctors usually issued a certificate of natural death and did not report euthanasia. Since 1986 the number of reported cases of euthanasia (to the police, the medical examiner, or directly to the public prosecutor) increased. The table, which is based on

the annual reports of the public prosecutor and an announcement of the minister of justice during parliamentary debate, shows that in 1986, 84 cases (3%) were reported; this number increased from 454 (17%) in 1990 to 1322 (49%) in 1992 (percentages are based on the assumption that the number of cases has not increased—in 1986–89 the number of cases in general practice was stable).²⁵ This increase is spectacular and can be ascribed to the careful prosecution policy of the public prosecutor and the notification procedure of 1990. It is estimated that about a quarter of doctors will refrain from notifying the medical examiner owing to the burden of legal review or the notion that euthanasia is something between the doctor and the patient, from which the legal system should stand side.^{14 18}

The table also shows that the percentage of prosecutions has decreased. By far the largest number of cases led to dismissal. In 1983 proceedings were instituted in two out of 10 reported cases, in 1984 in three out of 19 cases, and in 1985, four out of 31; in the following years the proportion of prosecutions decreased to almost nil. This decrease is the result of three developments. Firstly, the need for test cases has decreased since a body of jurisprudence developed during the 1980s.²⁶ Secondly, doctors are better informed about the requirements thus formulated and have improved their decision making and their practice. Thirdly, it cannot be ruled out that doctors tend to report those cases in which they are quite certain that they will not be prosecuted. However, the conclusion that all unreported cases do not meet the standards is not justified; research indicates that most of these cases meet the substantive requirements.¹⁸

The public prosecutor is clearly facing a dilemma: cases with shortcomings—which need to be reported the most urgently—might tend to be reported less frequently. About half of doctors do not (yet) report, and a substantial minority will probably not do so in the future. The legal principle that no one needs to incriminate himself or herself, and the viewpoint that euthanasia and assisted suicide should be kept within the confidential relationship between doctor and patient, explains such a standpoint. A stricter prosecution policy will further limit the willingness of these doctors to report. A less stringent prosecution policy, however, will reduce the penalisation of euthanasia to a mere formality. These problems will not be solved by the notification procedure that has now been legally embedded. Therefore the Royal Dutch Medical Association argues that from the viewpoint of regulation it is sensible to get euthanasia and assisted suicide out of criminal law. Since this has not happened in the Netherlands, it seems appropriate to create an additional procedure aimed at quality control.

Shades of grey

Bill 22572 also extends the notification procedure to cases of ending life without an explicit request. In the face of criticism from the Senate, the Dutch government agreed to make a distinction in the notification procedure between cases with and without an explicit request, also indicating that in cases without a request doctors as a rule will be prosecuted.²⁴

It is estimated that ending of life without an explicit request has occurred in about 1000 cases a year, with information available about the patient's wish in 59% of the cases.²³ According to Van der Maas *et al* there is also a boundary area of 2% of all deaths in which it cannot be distinguished clearly whether euthanasia, ending of life without an explicit request, or alleviating pain and symptoms with at least an oblique intention of ending life were involved.¹⁴

In the discussion of medical decisions of this kind it

Number of cases of euthanasia reported to the public prosecutor and number of dismissals and prosecutions, Netherlands, 1981–92

Year	No of cases reported	No of dismissals	No of prosecutions*
1981	4	NA	NA
1982	7	NA	NA
1983	10	8	2
1984	19	16	3
1985	31	27 (1)	4
1986	84	82 (1)†	2
1987	126	123 (1)†	3
1988	184	182 (1)†	2
1989	338	337 (1)†	1
1990	454	454	
1991	591	590	1
1992	1322	NA	4

NA Data not available.

*Immediate prosecution or further prosecution after an inquest.

†Dismissed after inquest.

must be kept in mind that the difference between the notions of explicit request and involvement in the decision making process, or consultation, is not always very clear. What can be clear enough for doctor and patient can be vague and insufficient from a more strictly legal viewpoint. Furthermore, the intentions of the doctor cannot just be summarised as shortening life or ending life, although this is one way of describing what is brought about. Their intentions could be described differently, for instance as diminishing suffering and hoping for a short dying time.²⁷

Despite these remarks it is quite clear that—if possible—decisions with the explicit intention of ending life should be discussed with patients more explicitly before they become incompetent. Perhaps it is needless to say that ending the life of a patient without an explicit request must remain a criminal offence, although it cannot be excluded that a court will accept an appeal to force majeure in circumstances of exceptional suffering.²⁸ Many have rightly criticised the extension, through the new act, of the notification procedure in these cases.²⁹ It has created the false impression that the ending of life without an explicit request can be as legitimate as euthanasia and assisted suicide.^{23–25}

Conclusion

The Dutch practice of euthanasia is not fuelled by a scarcity of health care resources. Most such deaths take place at home in patients with a life expectancy of less than a month, after hospital treatment has proved ineffective. The number of cases of euthanasia in nursing homes is very low. Finally, the whole Dutch population is insured for the costs of protracted illness, and financial incentives do not influence medical decisions concerning the end of life.

It has also been argued that insufficient treatment for pain is given in the Netherlands; this is a reason, the argument continues, why patients are forced into an unnecessary wish for euthanasia. Whether or not this is the case is not of crucial importance for the practice of euthanasia, since in only about 5% of cases is pain the most important reason for requesting euthanasia. There are no indications that palliative care in general is insufficient.

Will the “Dutch experiment” lead downhill inevitably? This article has shown that we are now confronted with at least two important issues: the presence of cases of ending of life without an explicit request and the existence of a related “grey area,” and the dilemma of the gaps in reporting of cases to the public prosecutor.

The tendency in the Netherlands is, however, not downhill but uphill. This can be concluded from the substantial increase in reported cases; the increased awareness of the requirements in cases of euthanasia; and the awareness of the existence of cases of ending of

life without an explicit request, and therefore the possibility of addressing this issue and diminishing this category by securing patients' wishes before they become incompetent (for example, by the use of living wills).

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Guidelines for paediatric life support

Paediatric Life Support Working Party of the European Resuscitation Council

The paediatric life support working party of the European Resuscitation Council was set up in 1992 with the aim of producing guidelines for basic and advanced paediatric resuscitation that would be acceptable throughout Europe. The commonest cause of cardiac arrest in children is problems with the airway. The resulting difficulties in breathing and the associated hypoxia rapidly cause a severe bradycardia or asystole. In contrast, adults have primary cardiac events resulting in ventricular fibrillation. This important difference in the pathogenesis of paediatric and adult cardiac arrest is reflected in these European Resuscitation Council guidelines, which complement those already published for adults.

Reported outcomes of cardiopulmonary resuscitation in infancy and childhood are variable.¹⁻¹⁶ Some of the variability arises from the poor distinction in many reports between a respiratory arrest, which more often has a good outcome,^{3,5,6} and a cardiac arrest, which has a much worse outcome.^{2,3,7,8} A poorer outcome is also seen when arrests occur outside hospital rather than in hospital.^{4,5,14} Overall, the outcome from cardiac arrest is worse in children than in adults¹⁵ because of the differences in the pathogenesis of cardiac arrest. In adults the commonest cause of cardiac arrest is heart disease but other causes predominate in children.

The commonest underlying cause of cardiac arrest in children is respiratory failure. This may result from lung or airway disease such as croup, bronchiolitis, asthma, or pneumonia, or from injury such as birth asphyxia, inhalation of a foreign body, or pneumothorax. Respiratory depression caused by prolonged convulsions, raised intracranial pressure, neuromuscular problems, or poisoning can also lead to cardiac arrest. The second commonest cause of cardiac

arrest is circulatory failure, usually due to loss of fluid or blood or to sepsis. Cardiac arrests of primarily cardiac origin, for example arrhythmias and pump failure, are uncommon in childhood and are seen most often in children in the intensive care ward of a paediatric cardiothoracic unit.

The poor long term outcome from many cardiac arrests in childhood is related to the severity of cellular anoxia that has to occur before the child's previously healthy heart succumbs. Organs sensitive to anoxia such as the brain and kidney may be massively damaged before the heart itself stops. In such cases cardiopulmonary resuscitation may restore cardiac output but the child dies from multisystem failure in the ensuing days or survives with serious neurological damage. Prevention of injury and earlier recognition of illness is clearly a more effective approach in these children. On a more positive note, there is a recent report of a higher incidence of neurologically intact survival after cardiac arrest.¹³

Different underlying causes of cardiac arrest exist at different ages. Asphyxia is the commonest cause of cardiac arrest at birth. In infancy, respiratory illness is the commonest cause, followed by sepsis, and in later childhood trauma becomes the commonest cause of cardiac arrest. We do not yet understand the mechanism of death in the sudden infant death syndrome, but current theories include an abnormal heat control mechanism. This has led to the recommendation in the United Kingdom that infants are nursed in the supine position.

In 1992 the European Resuscitation Council published its recommendations for adult basic life support and adult advanced life support.^{17,18} The present paper details the recommendations of the working party on paediatric resuscitation of the European Resuscitation Council. The first part of the paper gives the recom-

European Resuscitation Council

Members of the working party are listed at the end of this report

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